

Minutes of December 18, 2001

PHDSC Web-based Resource Center Work Conference Call

On the call:

Suzie Burke-Bebbee, Centers for Disease Control and Prevention (CDC) /
National Center for Health Statistics (NCHS) / Office of Data Policy and
Standards

Bob Davis, New York Statewide Planning and Research Cooperative System
(SPARCS)

Tom Doremus, Public Health Foundation (PHF)

Marjorie Greenberg, CDC / NCHS / Office of Data Policy and Standards

Vicki Hohner, Washington State Department of Health

Note: The minutes were edited for brevity and clarity.

General Discussion on the Consortium and Resources

Marjorie: The vision of what the Consortium could be doing, should do, and has the opportunity to do, was coming out in that call. The need for the services and products that the Consortium could provide is tremendous. It's so important to establish a common way of communicating. He asked about the new CDC Information Council. It is not off the ground at this point. Yes CDC is an important member the Consortium but the Consortium is not a CDC function. This is an organization that includes 32 members; it has to more than just the federal government, more than just the states.

Bob: I see us headed in the right direction, regarding our business case, and providing a central location.

Marjorie: We had a very good conference call yesterday launching what is now been called our Business Development and Marketing Work Group. Elliot and Walter are co-chairing.

In Elliot and Walter's group, we talked about four different needs for resources. One is the core functions of the Consortium - the meetings, conference calls, etc. Currently NCHS is supporting this. With our upcoming meeting in March we had hoped that this being the third year more organizations would be able to pay for their representatives travel expenses. Now it seems that fewer can, with the economy, fallout from September 11th, etc. I'm not sure at this point if we have the budget to cover all of the travel needs. Then there are Consortium projects specifically, such as the Resource Center and the Health Care Services Implementation Guide as examples in the second category. Third, there are projects that Consortium members are interested in pursuing related to health data standards, and ways in which we can help members partner with each other; maybe give them guidance on where to find support. Fourth, there are also other groups such as Sharp and WEDI that the Consortium wants to partner with.

We are talking about developing criteria for projects that Consortium members might want to bring forward to obtain endorsement. Some view that obtaining the endorsement of the Consortium could strengthen their hand in applying for funding. We were talking about using the Resource Center as a place to keep track of and catalog some of these potential or emerging projects. Let's say one state decided to do something along the lines of security, they could visit the site and see which other states are working on similar projects, and they could consider partnering with them.

Any reactions?

Tom: I think that anyway we could move this forward is a good idea. If we do not have something of substance, regarding project information of interest to a member, we could suggest tools at other Web sites that help meet criteria we establish (preventing us from re-inventing the wheel when possible), or identify other entities working on a similar project that might not fit our criteria, but may be useful to the information seeker.

Marjorie: I'm still working on CDC obtaining a representative to the Consortium and to NUCC.

X12 and HL7

Suzie: I talked to John at the National Committee meeting (he made a presentation about the NEDSS initiative), I asked when they were going to work on the pilot. He said that this had been moved to January.

I was talking to John about X12. When I heard they were only looking at clinical data, I thought of how demographic data, etc. would have been helpful to determine anthrax breakouts. He said the X12 and HL7 people should be talking. I asked what CDC was doing to look at X12 as a good reference for data. He said they were reviewing all their options.

Marjorie: I had been talking to Steve at the ANSI Health Care Informatics Standards Board (HISB) meeting. HISB had a strategic planning meeting in Albuquerque, New Mexico. HL7 was there, but not X12. I said to Steve that I don't think we have the luxury to wait 15 years for HL7 and X12 to become interoperable.

At the NCVHS meeting last week I asked - have you been looking at using administrative data, data from encounter records, as part of your Surveillance efforts? If so, consider making it possible to exchange X12 and HL7 records seamlessly.

Tom: Marjorie, do you know which of the two systems are used most by health departments, X12 or HL7?

Marjorie: It all depends on the source of the data. If it is administrative/financial data, then X12; if it is from clinical records, then HL7. But immunizations happen in encounters. They have an HL7 immunization message, but not many use it. Immunizations should be captured in encounters. A lot of data for registries comes out of encounter data. I think they need to use both.

Suzie: One of the issues that Simon C. brought up in the standards and security meeting was in the marriage between administrative and clinical data. We are writing a letter to the Secretary dealing with the Patient Medical Record Information (PMRI) and what the standards should be. At the forefront, with clinical data, it is HL7. There are other standards that we are reviewing. Simon thought it might be useful to put something in the letter about X12 and HL7. It was also brought up that it was a political issue that may be best left out of the letter.

Marjorie: HL7, at the request of their foreign affiliates, is coming up with standards for administrative data for the type of transactions that fall under HIPAA. This could result in duplicate standards for X12 and HL7. Bob, do you think that XML will help to solve this.

Bob: XML is a different construct. It is used as a type of middleware between a portal on the Web and a relational database. By tagging the information that you are sending, you to make the connection between where it belongs on the Web screen and where it belongs in the database. Both X12 and HL7 are changing along the way. HL7 is meant to be an internal message, so one of the problems that people in New York State implementing NEDSS is having is that one of the segments that is in HL7 can be interpreted in different ways by different people. The standard is meant to be flexible that way. In X12 segment is a segment.

Marjorie: I think Version 3 is supposed to correct that.

Bob: HL7 is saying that maybe the messages also need to go outside of an organization. When it goes outside of the organization it will have to become more like X12 and be more specific or it will not be standard.

Marjorie: The problem now is that other countries don't use X12, so they want to use HL7.

Suzie: I have heard that Canada is having some problems implementing the administrative add-ons for HL7.

Assessing Emerging Health Threats/Bioterrorism Events

Suzie: We had an individual ask what is the Department doing to work with the Homeland Security group.

Marjorie: Do you know the answer to that Tom?

Tom: No I don't, that is an excellent question. I couldn't hurt for me to check out what this group is doing with data standards.

Marjorie: The individual said that they were working with the localities on emergency preparedness and the standards were not there. They were wondering which standards to use. The National Committee on Vital Statistics is working on a session regarding the post-September 11 issues at the February meeting.

Bob: I had a meeting in New York City with some clinicians discussing bioterrorism and emergency department activities that we are doing in New York State. What came out loud and clear was that the clinicians do not have a way now, with the data that they have, to easily identify an event. It comes down to the clinician's gut feeling to be able to identify an event.

For the anthrax situation in New York City it came down to a problem of the response. This became problematic. You had different hospitals doing different things. They were doing it in a non-uniform way.

One of things that we're trying to accomplish with the Resource Center is to try and provide a central place for people to look for answers to their questions in terms of response to bioterrorism events for health data standards of etc.

There is a lot of development that's going on right now that may not be useful. They're going to be developing things for which there are no answers. Until the clinicians come up with the rules to identify an event, what is some data processing system going to do to help that?

Marjorie: I don't see our Resource Center having information about response to bioterrorism.

Bob: What we're trying to do in terms of standards is to centralize where people go for information on standards. A lot of the development for bioterrorism from my perspective should be places where people go to learn how to respond about bioterrorism; we should be focused on the response end because this is something that we can control.

Marjorie: What you mean by response?

Bob: After the anthrax events people wanted to know how to handle mail.

Marjorie: Do you see the Consortium involved in that?

Bob: No but I see us as having a similar function for standards. Having a central place for people to get their bioterrorism-related data standards questions answered.

Marjorie: That was a conversation that we were having with a local health representative. He said that at the local level they were trying to build a response capacity and were getting mixed messages. He said it seems that many of the national level groups working on response issues are not communicating with each other.

Tom: I wanted to further discuss how we were going to address the needs for standardized data to aid in recognizing the emerging health threats. I believe that strong funding is becoming available for bioterrorism preparedness, and we would do well to showcase the benefits of our efforts. I believe that the sooner that we explain how our standards work is married to the preparedness issue and ability to facilitate rapid assessment of emerging threats of a variety of natures, the further ahead we will be in line when the funds are made available.

Suzie: Do you think that the survey results will help to support this?

Tom: We have asked some questions around the preparedness issue. I believe the results of some questions will point us to specific data that organizations and agencies use for emerging health threat information, and thereby will help us better understand standards needs. By further investigation, we may determine data sources that would benefit greatly by the simplest of standards.

Marjorie: A year-ago everyone wanted to jump on the medical errors bandwagon. Many more are dying today from medical errors than from bioterrorism. Nonetheless, bioterrorism is no longer a remote issue. I think we need to learn a lot more in this area.

Tom: The Public Health Training Network (PHTN) has been putting on a series of training events on the issue of bioterrorism with archived versions available at <http://www.phppo.cdc.gov/phtn/>. There is also the main CDC bioterrorism site titled Public Health Emergency Preparedness and Response located at <http://www.bt.cdc.gov/>. Part of our job at the Public Health Foundation is to promote these PHTN training programs and the main CDC bioterrorism site.

Marjorie: A lot of what is presented at the sites is clinical information. We need to make the connection to data standards.

Tom: Hopefully the survey results will help us make some of those connections, including leads to address non-bioterrorism related, emerging health threat data.

Marjorie: Tom, is there a way that we can help make the emerging health threat questions stand out in the survey?

Tom: Yes, I will be happy to highlight these questions.

Vicki: I see bioterrorism data and standards as being linked. We need a standard way of reporting these data. We also need standard ways of defining these data. Data without standardized definitions are hard enough to track locally. When you try to engage in National Surveillance, the problem becomes even greater.

Suzie: Marjorie talked about our need to know what content we're going to populate the resource center with. Bob explained a real example of clinician needs in New York. I think it boils down to determining what they need and how best for them to obtain it. Not only is it important to determine the content, but then how do we make sure that the clinicians have access to it.

Bob: We divide the problem into two main parts in New York State. One is the identification of the outbreak. Two, what you do once you know about it. Regarding identification, it usually comes down to a clinician's gut feeling as to what is going on. Clinicians are having a hard time standardizing the elements they use to make their assessment.

Vicki: I would think it won't stop standards from being developed, but it will likely be a patchwork system, much like we already have.

Marjorie: It seems to me that any individual clinician may not see enough to connect the dots. That is why emergency departments are so important.

Bob: The clinicians are trying to determine combinations of data elements that work best.

Marjorie: There is going to have to be some capacity at local and state health departments to determine patterns from the data from individual providers and emergency departments.

Vicki: We have been talking with our epidemiologists who gave us some clinical symptomology. They feel that an electronic reporting system may not be fast enough since people have to take the time to enter the data...they often call it in when something is recognized.

Suzie: That is what John L. said to me. They need real-time data.

Vicki: Our manual reporting is sketchy. We don't get a lot of data for the events that are notifiable.

Suzie: I think that there are several policy issues that the Consortium can address that we've talked about here.

Bob: For our Resource Center, we want to create a model of how to bring disparate resources to one place.

Marjorie: Also we want to think about the standard ways of reporting and defining. What is not clear to me is the extent to which the Consortium could be an effective voice to get these different partners to talk to each other and agree on standardized ways of reporting and defining.

Bob: I think that this is the big role of the Consortium, to be a facilitator for this area.

Tom: I think it's helpful when agencies and organizations know who is talking as well as what they are talking about. It helps provide a sort of vacuum. If they see organizations identified that have the same needs, they may ask themselves why they are not listed. At the Resource Center, when we get information, we can advise the organizations or agencies, that we post, that we are highlighting their efforts. This may help to facilitate knowledge of the ever-expanding network of stakeholders to the stakeholders.

Suzie: Do you think that we have enough questions on the survey that will help us to address this?

Tom: I don't think that those questions are covered within the survey. I think there's several questions that need to be asked on that issue.

Suzie: It would appear that it would need to be a survey to itself.

Marjorie: I am wondering about meta-data registries for bioterrorism related information. Sometimes that can be the beginning of a way to work towards standardization.

E-Health Consortium

Vicki: In Washington State people are looking at developing an E-Health consortium. They are working on that through Evergreen State College and trying to focus on applications and electronic items, but they are also working on the bioterrorism effort. This is intended to be a national effort.

Marjorie: How do we keep from duplicating our efforts?

Vicki: Kathleen Connor and myself are just starting out. We have worked on a domain name; we are working on bringing people to the table, and on funding. We have been talking with Denise about it. We are interested in a better way of capturing reportable conditions. We are interested in creating a neutral non-profit think-tank that would put their products in the public domain.

Marjorie: What will their mission be in relation to the PHDSC?

Vicki: We are just in the formative stages, so your input would be helpful.

Suzie: Are they interested in E-Health for HIPAA issues only or in the broad sense?

Vicki: We are planning for HIPAA issues first, then we would expand to broader areas.

Marjorie: Do you see these activities duplicating each other or complimenting each other?

Vicki: It depends on which way we go. There may be some overlap. There has been nothing definitive. E-forms are being developed and we are looking at developing an educational institute that looks at policy aspects.

Marjorie: Is there a mission statement?

Vicki: I will see what I can obtain from Kathleen to send you. She is hoping that we could establish a greater tie-in with CMS.

Marjorie: Sally Klein was on call yesterday and talked about the importance of greater collaboration between Medicaid and public health.

Vicki: We would like to determine how best to work with the Consortium.

Suzie: The conversations that I have been having with Kathleen have included the possibility that the PHDSC could endorse her concept of the E-forms. I do not understand how the forms would work with public health, because the players are so different.

Marjorie: Were E-forms set up to handle HIPAA transactions?

Vicki: They were set up to report billing data and to handle HIPAA transactions. They could be set up easily to have this same mechanism to obtain surveillance data. We have also looked at the possibility of people collecting and reviewing the billing data as a way of getting to reportable conditions.

Marjorie: Who would be members of the E-Health consortium?

Vicki: Some of the same organizational members as are in PHDSC.

Marjorie: Why not become part of the PHDSC?

Vicki: Our concept is broader than public health. It will be focussed on developing applications, policy, and coursework.

Suzie: Would it be something that included collaboration with PHDSC?

Vicki: Yes, or PHDSC can be a partner at the table.

Suzie: It sounds like there are similarities, but there are enough differences that you can justify establishing a separate environment to work in.

Vicki: Yes, but we want to develop applications that serve multiple needs (public and private).

Bob: When I first talked to Vicki and Kathleen, I understood that they were looking at shared tools like the E-business forms. I have not looked at the PHDSC as an organization that focuses on the development of tools. We have been primarily developing policy statements and approaches. If an organization is going to develop tools that are promoted in a public area, I do not see a conflict, but now there may be a grain of conflict if that organization also engages in policy along the same lines as PHDSC.

Vicki: It would be E-Health policy as well as public health. We would work to stay neutral.

Suzie: Before we get together I will need to know more about the structure that you and Kathleen are starting to build. I think the educational component is fantastic.

Vicki: We are in the early stages. There is already interest in developing a health policy curriculum with Evergreen College.

Suzie: It may be an opportunity for your new organization to tap into other parts of organizations that belong to PHDSC.

Vicki: We could discuss a conference call on this issue (separate from WRCWG).

Establishing a Home for the Web-Based Resource Center

Tom: A lot of these issues are obviating the need to establish a home for the Resource Center. We need a place to start posting and a place to start accepting material. I believe we need a new domain that is separate from NCHS (the full Consortium site) or we need to see if it can reside as part of the Consortium site. I think the rest of the members will be interested to know, in March, exactly where this site will be.

Marjorie: We may want to present some options and get Steering Committee feedback.

Bob: Tom, what would you feel would not be appropriate for the main Consortium site, but would be appropriate for member sites.

Tom: The survey is an example. Since the Federal Government can not easily host surveys; I am currently posting the survey on my personal site. Also, we may want to place programs on the server that hosts our site without fear of harm to other non-Resource Center Web pages on the same server.

Marjorie: We can of course link to the main Consortium site and to the many other sites that meet with our mission. Having a separate site would decrease the likelihood that people would think that it was a CDC activity.

Bob: So this gets us right into the funding issue.

Marjorie: I was thinking of a consortium of organizations within the Consortium - national organizations but not government to collectively host the site. However, it will be a challenge to find neutral territory.

Suzie: To get funding for this core group would be a grant writing process unto itself.

Marjorie: The main Consortium site could host a prototype as long as it didn't have things like surveys on it. We should develop a prototype for funding purposes. Tom, do you agree that we could develop a temporary home for the prototype?

Tom: I do agree but one of things that I think is important is if we come up with our own domain name we can go ahead and register the name at a place such as www.register.com. Then we can have the domain name point to the server of our choice (that we would rent if we had it point to our separate IP address). The reason that this is important is that as people start a link to a particular domain name they expect it to remain there. We would also benefit from natural marketing forces such as ease of finding the site and frequency that the domain name is heard and used in messages

Suzie: So are you saying that a new domain name can point to a government site or to a private industry site.

Tom: Yes

Marjorie: What does it cost for a new domain name?

Vicki: We paid sixty dollars.

Tom: It is reasonably inexpensive (63 dollars for two years for ".info"). I think sooner than later is important, since good names are being taken. I like the ".info" domains because of the nature of our planned site.

Suzie: I like ".info" because it is benign.

Tom: My suggestion is that we all go to Register.com and test some name ideas, pitch them to the Work Group via the listserve, then vote on them during the next call.

Marjorie: Once we have a name, then what?

Tom: We would want to determine where we want the domain to point to at any given time after that. We would be paying rent (e.g. 35-50 dollars per year) to reserve the domain name for our use. If we do not have the domain name point to its own site on a server separate from CDC, we may have to pay minor charges (e.g., 50 or less per year) for URL forwarding to have the domain name point to a file on the CDC server that we would designate as the Resource Center homepage. A separate site can be as inexpensive as 10-20 dollars per month.

Interim Report

Suzie: What did you want to discuss about the Interim Report?

Tom: As I understand it, I need to identify our major accomplishments and there was something written into the deliverables regarding navigation at the Resource Center. (Tom reviewed the major accomplishments with the group).

Suzie: I would like Michelle to help with the web design work. She has done great things with the Consortium site.

Tom: Sounds great. I realize that she has been doing a lot of self-study and hands-on with web design.

Future Calls

Tom: We need to determine if we are to meet monthly on the future calls. If so, I need guidance on availability of the CDC bridge.

Marjorie: Yes, at least until the March Consortium meeting.

Tom: I would appreciate that those who are unable to be on a call respond to the agenda, other handouts, or minutes, as they become available. I appreciate those that made an effort to advise us of their inability to be on this call, either before, or soon after the call. Note: Helen expressed her regret that she must

resign from the Work Group, because of a taxing load at her regular job. She did ask to remain on the listserv.

Preparing for the March Steering Committee Meeting

Marjorie: It would be helpful to discuss what we want to accomplish between now and the March meeting. We have the survey posted now.

Tom: I believe that we can have the analysis of the survey done by the March meeting. We can integrate the results into the white paper. I think we will be able to tell the Steering Committee what our basic vision is, about the annotated sites, how the site will be accessed, where the home will be (domain name), how searches will be performed, basic Navigational features, etc.

Marjorie: One of the big questions is how are we going to populate the site with information and what kind of information will we provide. Ultimately the Resource Center will need funding, although it can start small.

Bob: The survey will help illustrate the interest that people have. I agree, we can present as our vision what we have developed to date, integrating the results of the survey. Then we can have a group discussion at the meeting.

Promoting the Survey

Marjorie: Regarding the survey, how do we plan to promote it.

Tom: I wanted to ask the members of the Consortium to send a message to their members/constituents and place a link to the survey on their Web sites. Also I would ask that they provide feedback on how they have gone about this (i.e., send me the web address of where a link is posted and provide an idea of the number that received a direct message from their organization). This information will prove valuable for our white paper and future surveys.

Vicki: I have sent out survey information to our local health contacts.

Tom: I have a link posted from the PHF site and we will be sending out an e-mail message to several thousand contacts via PHF E-News.

Marjorie: How about a deadline for completion of the survey?

The group discussed this and decided on January 31 as the deadline. Michelle will develop and send letters to members of the Steering Committee containing suggested language for messages to their members/constituents and language for Web links.

Adjourn